

## Quality of Life in Schizophrenia: What is Important for Persons with Schizophrenia in India?

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### ABSTRACT

**Background:** Quality of life (QOL) is a multidimensional construct and is increasingly recognized as an important outcome measure. Schizophrenia runs a chronic course and is a disabling mental disorder. Assessment of QOL using currently available scales for schizophrenia may not be culturally relevant. **Methods:** In phase one, patients with schizophrenia using psychiatric rehabilitation services, caregivers, and mental health professionals were interviewed qualitatively to identify factors that are important for QOL of patients. In phase two, 40 patients with schizophrenia were recruited consecutively from the outpatient department and asked to rate the importance/relevance of the above items for QOL on a Likert scale. **Results:** Themes that emerged were work, family's understanding about illness, stigma, financial issues, social life, social standing, religion and spirituality, medications, physical health, mental health and symptoms, recreation and leisure, and independent living. Work and family's understanding of illness were considered as moderately or very important by all patients in phase two. **Conclusions:** Work is very important for all patients with schizophrenia for their QOL. The themes derived from this study could guide the development of a scale for QOL that is relevant to the Indian context.

**Key words:** Indian context, Quality of life, schizophrenia

**Key messages:** Patient perspectives about factors important for QOL in schizophrenia include multiple domains such as work, family's understanding of their illness, physical health, mental health, stigma, and finances. Factors such as recreation, social life and standing, living independently, religion, and spirituality also seem to be important for patient's quality of life.


Schizophrenia is a severe mental disorder characterized by three broad categories of symptoms: positive symptoms, negative symptoms, and cognitive symptoms. It generally runs a chronic course with heterogeneous outcomes. Schizophrenia is associated with significant functional impairment, challenges in community living,

and burden of disability.<sup>[1]</sup> In addition to the symptoms and impaired role functioning, schizophrenia affects many other spheres of living, such as interpersonal and socio-occupational domains.<sup>[1]</sup>

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The National Mental Health Survey of India, 2015-16 reported a lifetime prevalence of 1.4% and current prevalence of 0.5% for schizophrenia.<sup>[2]</sup> Family, social, and work life were significantly affected, leading to disability in these domains in two out of three persons with psychosis in this survey.<sup>[2]</sup>

The concept of quality of life (QOL) is pertinent to conditions that are chronic in course and when treatment is required for a long period of time.<sup>[3]</sup> There are many commonalities that schizophrenia shares with other medical disorders that run a chronic course as far as the QOL s concerned. Yet, there are differences such as the effect of psychopathology and symptoms and the side effects of medications on QOL which may be unique to schizophrenia.<sup>[4]</sup> QOL is now understood to be a multidimensional construct that encompasses both subjective and objective measures.<sup>[3]</sup> The WHO definition of QOL includes person's physical health, psychological state, level of independence, social relationships, personal beliefs and environment, all of which are shaped by culture and value systems.<sup>[5]</sup> Culture in this context refers to the unique behavior patterns and lifestyle shared by a group of people which distinguish it from others. Culture may significantly influence symptoms, help-seeking behavior, and the course and outcome of schizophrenia. A study that compared Indian and Swedish patients reported that in a majority of the domains, QOL was the same in both the groups.<sup>[6]</sup> The Swedish patients were more dissatisfied with social contacts compared with their Indian counterparts. The presence of joint and extended family system and close social ties seen in India may explain this.<sup>[6]</sup> A qualitative meta-synthesis of QOL studies in mental health problems (that included severe mental disorders) had identified six broad domains: symptoms, autonomy, belongingness, self-perception, activity, hope, and hopelessness.<sup>[7]</sup> Some domains such as spirituality, religiosity, and the role of the family in a largely collectivistic society in contrast to individualistic societies may be important determinants of QOL in Indian patients.

The information from caregivers has been used as a proxy and surrogate marker of QOL of patients.<sup>[8]</sup> This becomes important particularly when patients may lack insight. Persons with schizophrenia who did not identify themselves as having an illness have been reported to have a higher QOL.<sup>[9]</sup> General psychopathology symptoms such as depression and cognition may also influence the QOL in patients with schizophrenia.<sup>[10]</sup>

Indian studies examining QOL in schizophrenia have used, more often, generic scales such as WHO-QOL BREF, which has been cross-culturally

validated.<sup>[11-13]</sup> Disease-specific scales such as QOL Scale for Schizophrenia have also been used in some studies.<sup>[8]</sup> To our knowledge, there are no disease-specific scales that have been developed in India for schizophrenia using perspectives of patients with schizophrenia.

## METHODS

The aim of the study was to examine what factors significantly affect the QOL in persons with schizophrenia and to quantify the relevance and importance of these factors. The study used mixed methods and was cross-sectional, involving a qualitative phase followed by a quantitative phase. The study was conducted at a tertiary care mental health setting with inpatient units, outpatient clinics, and specialty psychiatric rehabilitation services. Psychiatric Rehabilitation Services of the institute is comprised of a multidisciplinary team. The services provided include day care services, vocational—assessment, training, and placement—services, home-based rehabilitation planning, disability welfare benefits counseling, and community-based rehabilitation. The patients who use the services include both persons with mental illness and persons with developmental disorders.

The institutional ethics committee approved the study, and participants were recruited after obtaining written informed consent.

The qualitative phase involved in-depth interviews of patients with schizophrenia, caregivers of patients with schizophrenia, and mental health professionals with at least 5 years of experience. The interviews of five mental health professionals, three patients, and two caregivers were conducted in English. The remaining interviews that were not in English (either in Kannada or Hindi) were translated to English and subsequently back-translated to the vernacular language to ensure that the data was interpreted for the intended meaning. We included patients who were clinically diagnosed with schizophrenia (ICD-10) utilizing the day care services at the center and able to give a valid interview. Patients with intellectual disability or other disabilities as per the Rights of persons with disability (RPWD) Act, 2016, as comorbidities were excluded. sociodemographic details, clinical global impression-severity (CGI-S) scores, and the positive and negative symptom scale (PANSS) scores were documented. All interviews were audio-recorded and transcribed verbatim. The qualitative analysis involved a deductive content analysis approach as described by Elo and Kyngas.<sup>[14]</sup> The transcripts were manually coded by two investigators for triangulation, and themes were identified. The data reached saturation with the

inclusion of six patients, six caregivers, and six mental health professionals.

Forty patients with schizophrenia utilizing the various services at the center were asked to rate the importance/relevance of each of these factors for their QOL on a Likert scale, in the quantitative phase.

## RESULTS

All the interviews with patients, caregivers, and mental health professionals were carried out by the same interviewer. The interviewer was a resident fellow in Psychiatric Rehabilitation and shared a therapeutic relationship with three patients.

The qualitative phase included six patients with schizophrenia (four males and two females), with a mean age of 38.5 years ( $SD = 4.18$ ). Of the six, three patients were unemployed, one was married, two belonged to lower socioeconomic stratum, and four were from the middle socioeconomic stratum. Two patients were graduates, three were educated up to high school, and one patient was a postgraduate. The mean duration of illness was 12.6 years ( $SD = 4.71$ ). The mean CGI-S score was 3 (mildly ill) ( $SD = 1.15$ ), while the mean PANSS score was 35 ( $SD = 2.44$ ). All the patients had grade 4/5 insight and were adherent to treatment. Among the caregivers, four were graduates and two were high school educated.

The six caregivers included five males and one female. They were either a parent or spouse of the person with schizophrenia. The mean age of these caregivers was 55 years ( $SD = 9.33$ ), and the mean duration of their caregiving was 12 years ( $SD = 4.04$ ). The six mental health professionals interviewed included two psychiatrists, two psychiatric nurses, one psychiatric social worker, and one vocational instructor with more than 10 years of experience in training persons with mental illness. The mean experience of these professionals in their respective fields was 13 years.

The following themes were identified in the in-depth qualitative interviews:

1. **The importance of work:** Work was valued for enhancing self-satisfaction, providing a source of income, building self-esteem, aiding in socializing, and improving social value and standing. The following quote illustrates the importance of work for QOL: “We should be given a job so that we can mix with the people. The job will help us to get a secure place in the society because the job will bring some money. Creative portion of ours can be utilized. The job will also make us useful employees of an organization.” Any form of work, and a paid

job in particular, was viewed as an integral part of life. Work was also perceived to be a means of distraction from symptoms as well as a mode of engagement to improve QOL: “When you have some job, then you will have some responsibility, you will have some dignity, and you have the income also.” A mental health professional stated that having reasonable accommodation at workplace and security from job loss were of significant importance to patients

2. **Stigma** was observed to be an important barrier to perceiving a good QOL. This was noted in the context of socializing, marriage, and work. Self-stigma may play an important role, as exemplified in the following quote from a patient—“It’s, like all persons, I should attend functions, festivals, and rituals. I also feel happy about going along with my family, but I feel what people will think about me—that kind of inferiority complex prevents me from going anywhere. I am not able to mingle with people. I feel, what will people ask? What will they say? That will be bothering me from inside.” A mental health professional stated that the label of a psychotic illness like schizophrenia might be more stigmatizing than depression. One of the patients described locking herself in a room because she was being labelled “mental” in her locality. The father of a patient with schizophrenia felt that stigma would affect a person’s self-confidence and may even lead to a relapse, further worsening the QOL
3. **The role of family members, their acceptance and understanding** of the patient’s condition was emphasized recurrently in the interviews. The importance of a caring and concerned family in improving his QOL was iterated by a patient with schizophrenia in the following words—“If I get love from my family, it’s more than sufficient. Now, my mother hates me so much. How will others motivate me if my own mother and brother abandon me.” Participants—particularly patients—underlined the importance of families’ understanding of the mental illness and the importance of families’ help and support in getting better symptom control either by reassuring them or by taking them for treatment during periods of relapse or crisis. For a woman with mental illness, having a better QOL meant “settling with her family” and the need to “get love from family”
4. **Mental health and control of positive symptoms** matter to most patients and their caregivers as far as an improved QOL is concerned. A patient with a fair degree of insight into his symptoms spoke about the impact of symptoms on his life—“There are certain voices which keep on mocking at me, teasing me that I’m getting less salary. I feel as if they are trying to phone my relatives. They are also

phoning each other behind my back. Because of this, I am unable to study and concentrate.” Father of a lady architect diagnosed with schizophrenia stated that mental health was the most important determinant of a better QOL. Giving the example of his daughter, he observed that—due to symptoms—“she cannot take decisions. She does not know what is good and what is bad... She will never come back to her original position in life... What she has lost is lost.” Another caregiver said, “Everything depends on mental health. If your mental health is not good, you cannot enjoy life in any way...f your mental health is good, you will enjoy everything—you will talk correctly and think of yourself and others.” A psychiatrist who participated in the study noted that a mental illness like schizophrenia could take away the very “essence of quality in a patient’s life.” He went on to add that complete deliverance from symptoms would be the ideal scenario, but “recovery they say is a process, and there is no clear endpoint.” The father of a person with schizophrenia felt that “experience of happiness” is a fundamental necessity for a good QOL

5. **Medications and their side effects:** A caregiver opined that medications helped in his son’s recovery from symptoms after seven years of untreated illness. He reported that “this treatment has given him a new life; his life had become useless... The treatment has restored happiness in his life.” Patients also complained about side effects such as tremors and drowsiness as being impediments to enhancing their QOL. For example, a patient observed, “I am taking medications now....and it is making me sedated and lazy, I am not able to walk very fast, I feel tired, and there is no enthusiasm... This should not be there. I think a better life will be a medicine-free life and when I am completely cured.”. A mental health professional alluded to the financial costs of treatment in the following words—“The cost of the medication itself can be posing a burden. So, somebody is earning, and spending 20% of their expenditure on medications ... This is a significant issue”
6. **The role of physical health and lifestyle:** Physical activities and good physical health, as a factor promoting a better QOL, mattered to many patients and caregivers. This included activities that reduced stress, in addition to the enjoyment involved in activities such as trekking, exercise, and cycling. Physical illnesses that are comorbid with schizophrenia also play an important role in the QOL, as observed by this patient who is on treatment with a second-generation antipsychotic, “The first thing is, diabetes should not be there. What you call ‘body mass index’ should be normal.

In my case, it is more than 35. It means I am obese. I do not do hard work, I cannot walk fast.” Staying away from substance use was also viewed as important for a good QOL. Substance use was viewed as a “bad habit,” as something censored by religion, as well as something impacting health and family

7. **Finance and money** were noted to be important factors in determining the QOL, from fulfilling basic needs to affording luxuries and more material needs. Factors such as cost of living and financial stability mattered to patients and their caregivers—“In our current life, whatever we earn is not enough for the family. Now everything has become costly. All prices have gone up. For poor people like us, we will not be able to buy anything, what we feel (like doing), we cannot do (are unable to do).” A patient reported—“only when we are financially stable, there is value for us; without money, we cannot do anything. No work can happen. For everything, money is required.” Another patient reported, “Nobody can do anything without money... if I look at my future, I should earn money. Otherwise, life becomes very difficult.” A caregiver who had three members in his family with mental illness to care for stated, “If you want to buy anything, if you want to purchase ration, you need money for it. We might travel sometimes, we may have to purchase some clothes, we have to cook and have food in house. Without money, we will not get any ration”
8. **The importance of confidantes and companionship:** The value of social relationships for QOL was recurrently emphasized across all three groups. A mental health professional, while summarizing the need for a social life, stated, “Usually, people want to be acknowledged by other people or want to be loved by other people. They want to be in touch with people so that they can share their feelings or share their life. It’s no exception for any person with schizophrenia.” Having friends or close family members to share feelings and thoughts was observed to be relevant to enhanced QOL. The importance of working on social aspects of rehabilitation during the recovery journey cannot be underemphasized, as illustrated in this quote: “Social relationship is important... When I got affected with schizophrenia, I was between the four walls. I never used to come out. When I started the rehabilitation program in NIMHANS, I started mingling with people of my kind. People had different kinds of illnesses—mental retardation or mental illness. Slowly, I started communicating with mentors over there. When they got confidence in me, they assigned me to different jobs.” Marriage was viewed as a social need, a source of support, and as a method of socially and culturally



sanctified companionship. A person diagnosed with schizophrenia, while emphasizing the need for marriage and companionship for his life, stated: “I am single right now. I should be sharing my life with someone. I think of having a partner in life to share things. To talk things. It will make me feel better.” The lack of opportunities to marry when mental illness is disclosed or known was viewed as detrimental to this domain of QOL. Sometimes, these are coupled with worries of who will take care of them in the future. For example, a 33-year woman with schizophrenia said, “See, I am already 33. In 2 years, I will be 35 years old. That is the last when girls will get married. Everybody will get old. Then who will look after me? My brother will be there for me only till he gets married. After his wife comes, then what will happen?”

9. **Religion and spirituality:** The patients and caregivers emphasized the role played by the practice of yoga and partaking in religious activities such as praying, sandhya-vandana or meditation, and listening to devotional songs as important for building “inner strength and confidence,” fostering recovery, and enhancing the QOL. A psychiatrist commented on the importance of spirituality in the Indian cultural context and how it plays a big role in providing “a sense of meaning, sense of meaning for existence itself.” A caregiver who identified himself as a practicing Muslim emphasized the role of prayer both as a religious duty and a source of healing. Another psychiatrist spoke about the importance of spiritual needs and the avenues for fulfilling those needs and listed some examples such as being guided by a temple priest or an elderly spiritual Guru with wisdom and finding “solace” in spiritual or cultural explanations for barriers, to enhance the QOL. Another factor noted was from the Hindu philosophy of Karma—illness as a retribution for “something done in the past.” A patient with schizophrenia summed up the importance of this aspect as a domain of QOL, as “We should have trust in God. If we believe, then most of our work will be easy—there will be no obstructions. Even if humans hate us, God will never desert us. That divine strength will do good for us, I feel”
10. **Recreation and leisure:** Playing games, engaging in hobbies such as reading books, watching cinema, attending social gatherings, painting, going to a library, and listening to music were most common examples of recreational and leisure activities valued as important for the QOL. One patient described the advantages of recreation by stating, “I am engaged. There is entertainment. We are going to different places, meeting different people, and seeing different things. It makes me feel happy.” Some patients looked at the messages in poems,

stories, and songs as aids to motivate them to make small changes in their lives

11. **Independent living:** Living independently, with little reliance on others for daily needs, from personal hygiene to complex activities such as instrumental activities and paid work, was an important need. This theme was closely linked to other themes on the importance of work, social life, and social standing. A caregiver reported the importance of independent living from the perspective of the wellbeing of both the patient and the caregiver in the following way—“He is not capable of looking after himself because of the nature of his illness. He has to be told, for example, when to have a bath, what clothes to wear for what occasion, etc.” and “Now she can’t take any decisions. We have to be constantly after her and before her sight (supervise her) to look after”
12. **Social standing:** The value of an individual in society is based on achieving certain goals expected for one’s age and gender such as meeting societal expectations of roles and responsibilities, working and earning, living independently, contributing to society, and working productively. These were considered important for QOL. We felt that this theme was closely intertwined and linked to several of the themes mentioned before. We deduced this to be a separate theme because the wholesome of a social standing is something that persons who were interviewed aspired and looked forward to. “Recovery”, for most patients meant regaining lost positions, lost incomes, lost skills, lost opportunities, and lost dreams. Patients and caregivers spoke about drift in occupations and social standing as very important to their daily lives and deeply impacting their QOL. A patient described this theme as a feeling of being “considered important and needed in society.”

### The importance of various themes for QOL

In the next phase of the study, the importance or relevance of these themes was rated by 40 patients diagnosed with schizophrenia on a 4-point Likert scale with an additional option of offering no comments. The 40 patients included 15 patients who were utilizing the daycare services, 16 inpatients, and nine outpatients; including 25 males and 15 females. The mean age of this sample was 45 years (SD = 11.86) with a mean duration of illness of 10.5 years (SD = 4.35), mean CGI score of 3 (mildly ill) (SD = 0.84). Thirty of these patients were unemployed, while the remaining were in some or the other form of fulltime or part-time paid employment. Only one of the patients was married and had children. Twenty-five patients belonged to the lower socioeconomic category, while the remaining belonged to the middle class. Table 1 illustrates the rating for all

the 12 domains. Since work was noted to be important for QOL in all the interviews, and it was also rated to be very important for all patients in the second phase, it was further assessed as to the primary reason for the relevance it held—whether as a form of engagement, a way to improve social standing, a source of income, a method to distract from symptoms, or any other reason. Of the respondents, 17 (42.5%) felt it was important as a source of income, 13 (32.5%) felt it was important for keeping themselves engaged, 5 (12.5%) felt work could serve to distract from symptoms, 4 (10%) felt that it was important for social standing and 1 (2.5%) stated that work would keep him happy.

## DISCUSSION

There is a lack of an equivalent phrase for “QOL” in Indian languages. Phrases such as “Jeevanada Gunamatta” in Kannada or “Jeevan ki Gunvatta” in Hindi are the closest, but they could also be taken to mean standard of living.<sup>[15]</sup> Indian translation of QOL may imply good characteristics of life or gunas, the specialty of life or visheshata, how good the life is or uttamata or standard of living.<sup>[16]</sup> Despite this, during the interviews, we found that the patients and their caregivers were able to understand the construct underlying this phrase and were able to provide perspectives on the various factors that could matter to the patients’ QOL.

It is recommended that QOL be measured using tools that are designed using a bottom-up approach, first examining qualitative perspectives of patients and caregivers.<sup>[4]</sup> Most scales that have been developed have not taken the views of the patients with schizophrenia themselves. The exceptions, however, are the Schizophrenia Quality of Life Scale<sup>[17]</sup> and the Quality of Life in Schizophrenia (QLiS)

questionnaire.<sup>[18]</sup> The studies that have been conducted in India on QOL in schizophrenia have either used generic scales such as WHO-QOL BREF that has been cross-culturally validated<sup>[12]</sup> or have used schizophrenia specific scales such as Quality of Life Scale for Schizophrenia that has been developed in the west.<sup>[6]</sup> There is a need to develop scales that are culturally congruent and relevant. This study is a first step towards designing a QOL tool for schizophrenia that is relevant to our population. We have additionally utilized the perspectives of mental health professionals who came from diverse backgrounds.

Many of the themes identified in the qualitative phase are very similar to the factors that have been found to be associated with QOL in developed countries. For example, factors such as stigma related to schizophrenia and mental illnesses, the influence of symptoms and symptom control, drugs and their adverse effects, financial and economic status, social relationships and family have been associated with QOL in schizophrenia.<sup>[19]</sup> The themes also encompass many domains covered in the WHO definition of QOL in general.

The disadvantage of many of the questionnaires that have been used to examine QOL in schizophrenia is either that they are too lengthy or that they include items borrowed from generic scales of QOL. The items of the disease-specific QOL scale<sup>[17]</sup> which have been adapted and used in India in patients with schizophrenia do not examine domains such as symptoms, side effects, recreation, leisure, and spirituality. Factors that are assumed to be “clinical”—such as symptoms of the illness and side effects of medications—have been traditionally ignored in QOL scales, but these were subjectively important to our patients.

Previous studies that examined the QOL in schizophrenia in Indian patients have provided, compared with the developed world, explanations that are sociocultural in nature to explain the differences in QOL. The explanations provided have included the presence of joint families in India, sharing of income among family members, availability of social support from extended families, lack of emphasis on education, and low priority given to recreation and leisure.<sup>[6,8,20]</sup> These may, however, be changing, following the trends of social changes that have happened in India over the last two decades.<sup>[21]</sup>

Our study indicates that factors such as work, physical and mental health, independent living, and recreation and leisure seem to be moderately to very important to our patients’ QOL. Furthermore, work seemed to be very important for the QOL for all the 40 patients in

**Table 1: Importance of different QOL domains for patients with schizophrenia**

Domain	Not or mildly important - n (%)	Moderately or very important - n (%)
Work	-	40 (100%)
Family’s understanding	-	40 (100%)
Physical health	2 (5%)	38 (95%)
Mental health and positive symptoms*	4 (10%)	34 (85%)
Independent living*	5 (12.5%)	34 (85%)
Financial issues	7 (17.5%)	33 (82.5%)
Medications	7 (17.5%)	33 (82.5%)
Social standing*	6 (15%)	32 (80%)
Social life*	8 (20%)	31 (77.5%)
Religion and spirituality	9 (22.5%)	31 (77.5%)
Recreation and leisure*	8 (20%)	31 (77.5%)
Stigma*	22 (55%)	16 (40%)

\*Remaining patients had no comments. QOL: Quality of life

this sample, for purposes of providing a source of income and to be engaged in some form of activity. Religion and spirituality emerged as a recurrent theme in the qualitative phase and were found to be very important for 57.5% of the patients. A previous study from north India had found that religiosity and spirituality affect the QOL in patients with schizophrenia.<sup>[22]</sup> Spiritual aspects need to be, therefore, considered when evaluating the QOL in schizophrenia.

In contrast to a life-threatening condition such as cancer wherein factors such as peace of mind and spirituality were considered most important,<sup>[23]</sup> in this study involving patients with schizophrenia from the same culture, more material aspects such as work and family's understanding were considered very important.

There is now a greater emphasis on making services recovery oriented. Recovery, in this context, is not mere amelioration of symptoms but has a very unique personal meaning encompassing various other factors that matter in the process, such as livelihood, education, social life, spirituality, and companionship.<sup>[24]</sup> The focus of service delivery will have to include all factors that are important for the QOL of patients with schizophrenia. In the background of the importance given to work in this study sample, and also in the context of it being closely related to other themes identified, such as financial status and social standing, there is an important need to focus on providing vocational rehabilitation services to patients with schizophrenia. In India, there is a dearth of such services that comprehensively provide rehabilitative care.

The trustworthiness of this study is enhanced by the following: three groups of key informants were interviewed to triangulate the data; two investigators coded the data and analyzed it. Additionally, in the second phase, respondents from the same setting validated the findings of the qualitative phase. This was a tertiary care hospital-based study; hence, the generalizability of the findings to other settings may be limited. Other factors that limit generalizability were that two-thirds of the patients and caregivers in the first phase were graduates, and the study included patients who had been referred for specialty rehabilitation related services. Therefore, their attitudes towards work may have been different than those of a community-based or general hospital-based sample.

## CONCLUSIONS

The patient perspectives about QOL in schizophrenia in our sample include multiple domains such as

livelihood, family, physical health, mental health, stigma, and finances. Factors such as recreation, social life and standing, living independently, religion, and spirituality also seem to be important for our patient's QOL. Work was very important for all the patients in the second phase of the study. This study could guide the development of a scale for QOL that is relevant to our population with schizophrenia. The study also highlights the imminent need to develop recovery-oriented services that include vocational rehabilitation services, as work seems to be very important for our patients' QOL.

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## Conflicts of interest

There are no conflicts of interest.

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